



State of Caring 2026 Survey

Participant Information and Consent Form

Family Carers Ireland invites you to take part in our national State of Caring survey which examines the lives and experiences of family carers who provide regular unpaid help for a friend or a family member with a long-term illness, health problem or disability. This survey will establish a snapshot of the situation and priorities of family carers across Ireland in 2026. By taking part in the survey and sharing your opinions and experiences, you will help *Family Carers Ireland* advocate for greater recognition and support of family carers. Before you decide to take part, we would like you to understand why the research is being undertaken, what it will involve and how the findings will be used.

Why are we undertaking this research?

Family Carers Ireland is undertaking the State of Caring survey so we can better understand what it's like to be a family carer in Ireland in 2026. This will allow us to form a clear picture of the issues and concerns affecting family carers and will help to direct the advocacy and support work of *Family Carers Ireland* as well as acting as a resource for other stakeholders, policy makers and academics with an interest in caregiving.

Who should complete the survey?

The survey should only be completed by **people who currently look after, or give help or support to a family member, friend, neighbour or others (adults or children) because of either a long-term illness, physical or intellectual disability, mental ill-health, substance abuse or problems related to old age**. Since the survey provides a snapshot of what it's like to care in Ireland at the moment, only those currently providing care to a loved one are invited to take part. **Please do not complete the survey if you are a care professional, such as a paid home care worker, a care assistant or a nurse, unless you also care for a family member or friend outside of your professional job.**

How to complete the survey

If you choose to take part, you will be asked to complete the survey questionnaire. The survey is completely voluntary and anonymous. You do not have to answer any questions you do not want to. It should take approximately 30 minutes to complete the survey, which you can do at any time that suits you. Please complete the survey by March 4th 2026. You will be asked questions on the following topics:

- Yourself
- The person(s) you care for
- Access to services and supports
- Time off from caring
- Financial circumstances
- Loneliness and Social Isolation
- Your health and wellbeing
- Policy priorities

Are there any risks in taking part in the survey?

There are no direct risks associated with taking part. However, sometimes thinking about the sort of issues raised in this survey can create some uncomfortable or distressing feelings. If you need to talk to someone about this, please see the resource links and free phone helpline number at the end of this information leaflet and also included at the end of the survey questionnaire.

Do I have to take part?

No, you are under no obligation whatsoever to take part in the research. Your decision to participate (or not) will in no way impact your current or future relationship with *Family Carers Ireland*. Completing the survey is completely voluntary. If you decide to take part, you are still free to withdraw at any time without giving a reason. Simply close the survey. However, once you submit the survey you cannot withdraw as the surveys are anonymous.

Confidentiality

All the information you provide will be strictly confidential. Your identity will not be available to anyone as all surveys are anonymous and cannot be traced back to you. **Please do not write your name anywhere on the survey.** Paper questionnaires will be stored securely in a locked filing cabinet and confidentially shredded after the answers from your and all other surveys are inputted onto an encrypted and password protected computer. Data collected from online surveys will be stored on an encrypted and password protected computer. These procedures have been reviewed by *Family Carers Ireland's* Data Protection Officer and the Research and Policy Committee. For more information, please see our Privacy Policy (<https://www.familycarers.ie/privacy>)

What will happen to my data?

Data will be used by Family Carers Ireland in reports and presentations to highlight the impact of being a carer to the Government, to Local Authorities, the media and other stakeholders. It is intended that the results of this study will inform government policy and help us to work on your behalf to improve the services and supports that are available to you.

If you agree, *Family Carers Ireland* may in the future share the anonymised dataset with academic researchers/institutions who can interpret the survey findings and provide a deeper analysis into subsections of the data collected. Should *Family Carers Ireland* agree to share the anonymised dataset with academic researchers/institutions they will have access to anonymised data only, ensuring survey participants are not identifiable. Any decision to share data would also require approval from *Family Carers Ireland's* Research and Policy Committee, and if/where necessary approval from the relevant academic partners Research Ethics Committee. In the event that *Family Carers Ireland* share anonymised survey data with external researchers, these researchers would only be given permission to look at areas that support the aims and goals of *Family Carers Ireland*. If you don't agree to the sharing of the anonymised dataset, you can still take part in the survey and your responses will be removed from any dataset shared with approved researchers.

The anonymised dataset will be kept (archived) by Family Carers Ireland on an indefinite basis. This dataset will be used for future trend analysis. The anonymised dataset will be stored on Family Carers Ireland servers.

How can I access the survey findings?

Family Carers Ireland will publish the survey findings in our 'State of Caring' report due to be published in the summer of 2026. The report will be available on *Family Carers Ireland* website



(www.familycarers.ie). Results will also be published in a number of reports or peer-reviewed articles and will also be presented at relevant conferences.

If you have any questions or concerns about the survey, please contact Joanne Murphy, Research Officer with *Family Carers Ireland* (jmurphy@familycarers.ie or 086 0326187).

If you need any help to understand or complete this survey, please contact us on our:

National Freephone CareLine

1800 24 07 24

- Learn about the [supports](#) that are available for family carers including free counselling, family carer events, young carer support etc.
- [Learn](#) about your Rights & Entitlements incl. Carers Leave & Carers Benefit, Grants available etc.
- [Access](#) free interactive e-learning modules, created with experts to help you in your caring role
- [Join](#) our FREE Emergency Scheme, which helps you, the family carer plan in the event of an emergency, such as contracting Covid-19
- [Enquire](#) about the provision of professional in-home care support in your area
- Freephone our [Careline](#) on 1800 24 07 24. We are always here to lend an ear, as ***we believe no one should have to care alone.***
- Join a community of family carers by becoming a member for €20 per year. Read about the benefits of having an FCI card [here](#).
- Join other family carers in our safe and secure [online forum](#) sharing tips, information and ask questions.
- Please see here the link for the contact details of your local Carer Support Manager [here](#).